

## CHSTRONG KIDS Phone Script

Hello, is this \_\_\_\_\_?

Hi, this is [Research Assistant name] from Boston University School of Public Health in partnership with the Massachusetts Department of Public Health.

I'm calling in follow-up to a letter sent by mail with information about a survey we are conducting about children born with heart problems. It's called CHSTRONG KIDS, which stands for the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG of Kids.

Did you receive the letter and survey?

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- If yes:

Do you have any questions about the survey? I'd be happy to answer them and, if you're interested, ask you the survey questions by phone, now or we could set up a time. It takes about 20 minutes to complete.

- If yes to telephone survey: *See Telephone Survey Introduction below*
  - If no to telephone survey: Thanks for taking the time to speak with me today. As mentioned in the letter, you can also take the survey online or return the survey by mail, and we'll send you a gift card worth \$20.00 for your time and effort completing the survey. If you don't have any other questions for me, then I hope you have a great day.
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- If no:

We are calling because your child was identified by the Massachusetts Department of Public Health Birth Defects Registry as a person born with a heart condition. We would like you to complete a short survey about your child, their quality of life, and access to healthcare. Your information will help us identify unmet needs of children born with heart conditions.

If you're interested, I can ask you the survey questions by phone, now or we could set up a time. It takes about 20 minutes to complete.

- If yes to telephone survey: *See Telephone Survey Introduction below*
- If no to telephone survey:  
Would you like to complete a paper or online version of the survey?

- If yes to paper/online survey:  
We can send you a new survey packet that includes both a paper survey and a QR code that you can scan to take the survey online. What address would you like us to send it to?
- If refusal (I.e. declined to participate via telephone and paper/online)  
Thank you for your time, we will remove you from the survey.

### Telephone Survey Introduction

If yes to telephone survey:

CHSTRONG KIDS is being conducted by Boston University School of Public Health in partnership with the Massachusetts Department of Public Health and Centers for Disease Control and Prevention (CDC). To learn more about this project, you can visit <website address>.

Across the country, thousands of parents and caregivers of children born with heart conditions are taking part in this survey. Everyone's answers are important to us and will add to what we learn about how heart conditions affect children. The findings from the survey may help identify unmet needs of children born with heart conditions and their caregivers and help families of children with heart conditions plan for the future.

As I said, the survey will take about 20 minutes to complete. None of your answers will be linked to your name or your child's name. Your name and your child's name will never be released as having a heart condition, having completed the survey, or having been asked to participate. We know your time is valuable. As a thank you for completing the survey, we'll send you a gift card worth \$20.00 for your time and effort.

Would you like to take the survey now or set up another time for us to call you?

- If now:

*Proceed with survey intro and survey questions.*

- If later:

When is a good time to call you back?

If you have any questions, you can call us at [<xxx-xxx-xxxx>](tel:<xxx-xxx-xxxx>) or find us on the web at <website address>

Thank you, we will call you on **xx, yy**.

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**Survey intro and survey questions**

*As explained in the letter you received with this survey, we are contacting you about this survey because our records show that your child was born with a heart condition. We would like to ask you some questions about your child, their health, and your family.*

*The survey should be completed by a parent or adult caregiver who lives in this household and who is familiar with your child's health and health care.*

*Please answer questions with information about your child with a heart condition only. **You may choose to skip any question you do not wish to answer.***

### *Your child's information*

1. In what month and year was this child born?

Month:

Year: \_\_\_\_\_

- a. January
- b. February
- c. March
- d. April
- e. May
- f. June
- g. July
- h. August
- i. September
- j. October
- k. November
- l. December

2. Is this child Hispanic or Latino?
  - a. Hispanic or Latino
  - b. Not Hispanic or Latino
  
3. What is this child's race? (Select all that apply)
  - a. American Indian or Alaska Native alone
  - b. Asian
  - c. Black or African American
  - d. Native Hawaiian or Other Pacific Islander
  - e. White

### *Your child's heart condition*

4. What is the name of the heart condition that this child was born with? (Select all that apply)
  - a. Aortic valve stenosis
  - b. Atrial septal defect (ASD)
  - c. Atrioventricular septal defect (AVSD) or Atrioventricular canal (AV canal)
  - d. Bicuspid aortic valve
  - e. Coarctation of aorta
  - f. Ebstein anomaly
  - g. Hypoplastic left heart syndrome (HLHS)
  - h. Patent ductus arteriosus (PDA)
  - i. Pulmonary atresia
  - j. Pulmonary valve stenosis
  - k. Single ventricle (double inlet left ventricle)
  - l. Tetralogy of Fallot (TOF)
  - m. Transposition of the great arteries (TGA)
  - n. Tricuspid atresia
  - o. Truncus arteriosus
  - p. Ventricular septal defect (VSD)
  - q. Other, specify \_\_\_\_\_
  - r. Don't know/not sure
  - s. No heart condition that I know of (***Please answer remaining questions to the best of your ability***)
  
5. *Has this child ever had surgery for the heart condition they were born with? Heart surgery will result in scars on the middle of the chest, side, or back.*
  - a. Yes
  - b. No
  - c. Don't know/not sure

6. *What type of information or help should be available to caregivers of children born with heart condition?*
  - a. *[Free text response]*
7. *When this child was first diagnosed with a heart condition, were you provided enough information on what this meant for their emotional, social and physical health?*
  - a. Yes
  - b. No
  - c. Don't know/not sure

### *Your child's heart doctors*

8. *When is the last time this child saw a heart doctor?*
  - a. Less than 1 year
  - b. 1-2 years
  - c. 3-5 years - **Go to question 13**
  - d. More than 5 years - **Go to question 13**
  - e. Never seen one - **Go to question 13**
9. *How many health care provider visits were with a heart doctor or at a cardiology clinic (clinic that only sees patients with heart conditions) in the past 12 months?*
  - a. \_\_\_\_\_ Numeric response
10. *Who are the majority of patients that this child's primary heart doctor usually sees?*
  - a. Children and adolescents (pediatric cardiologist)
  - b. Adults (adult congenital heart cardiologist or adult cardiologist) - **Go to question 12**
  - c. Don't know/not sure
11. *Has a doctor or other health care provider talked with you about when this child will need to see heart doctors who treat adults (adult congenital heart cardiologist or adult cardiologist)?*
  - a. Yes
  - b. No
12. *In the past 2 years, how often has this child's heart doctor:*
  - a. Spent enough time with this child? *[Always/Usually/Sometimes/Never]*
  - b. Listened carefully to you? *[Always/Usually/Sometimes/Never]*
  - c. Shown sensitivity to your family's values and customs? *[Always/Usually/Sometimes/Never]*
  - d. Provided the specific information you needed concerning this child?  
*[Always/Usually/Sometimes/Never]*
  - e. Helped you feel like a partner in this child's care? *[Always/Usually/Sometimes/Never]*
  - f. Discussed with you the range of options to consider for this child's health care or treatment?  
*[Always/Usually/Sometimes/Never]*

- g. Made it easy for you to raise concerns or disagree with recommendations for this child's health care? [Always/Usually/Sometimes/Never]
- h. Worked with you to decide together which health care and treatment choices would be best for this child? [Always/Usually/Sometimes/Never] - **Go to question 14**

13. *If this child has not seen a heart doctor in the last 2 years or ever, why? (Select all that apply)*

- a. This child felt well
- b. Did not think this child needed to see a heart doctor
- c. Doctor told me this child no longer needed to see a heart doctor
- d. Changed or lost insurance
- e. Moved to a different city or town
- f. Did not like this child's heart doctor
- g. Couldn't find a heart doctor
- h. I had too many other things going on
- i. There were issues related to cost
- j. I chose to postpone or cancel appointments due to COVID-19
- k. This child's heart doctor postponed or cancelled appointments due to COVID-19
- l. Other, specify \_\_\_\_\_

### *Your child's general health*

***If your child is younger than 6 years old, go to question 16.***

14. What is this child's CURRENT height? (***Answer in either feet and inches or meters and centimeters***)

- a. \_\_\_ Feet AND \_\_\_ inches
- b. \_\_\_ Meters AND \_\_\_ centimeters

15. How much does this child CURRENTLY weigh? (***Answer in either pounds or kilograms***)

- a. \_\_\_ Pounds
- b. \_\_\_ Kilograms

16. In general, how would you describe this child's health?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

### *Your child's medical conditions*

17. *Has a doctor or other health care provider EVER told you that this child has...*

- a. Anxiety problems [Yes / No]

- b. Depression [Yes / No]
- c. Developmental delay [Yes / No]
- d. Behavioral or conduct problems [Yes / No]
- e. Intellectual disability [Yes / No]
- f. Speech or other language disorder [Yes / No]
- g. Learning disability [Yes / No]
- h. Attention Deficit Disorder or Attention Deficit/Hyperactivity Disorder, that is, ADD or ADHD [Yes / No]
- i. Autism, Autism Spectrum Disorder, Asperger's Disorder, or Pervasive Developmental Disorder (PDD) [Yes / No]
- j. Diabetes [Yes / No]
- k. Down Syndrome [Yes / No]
- l. Other genetic or inherited condition [Yes / No]
- m. Heart failure [Yes / No]
- n. Other (specify) [Yes/ No] \_\_\_\_\_

18. Does this child have any of the following?

- a. Deafness or problems with hearing [Yes/No]
- b. Blindness or problems with seeing, even when wearing eyeglasses [Yes/No]

**If your child is younger than 6 years old, go to the next question (#19).**

- c. Serious difficulty walking or climbing stairs - [Yes/No]

### *Your child's healthcare needs*

19. Does this child CURRENTLY need or use medicine prescribed by a doctor, other than vitamins?

- a. Yes
- b. No

20. Does this child need or use more medical care, mental health, or educational services than is usual for most children of the same age?

- a. Yes
- b. No

21. Is this child limited or prevented in any way in their ability to do the things most children of the same age can do?

- a. Yes
- b. No – **Go to question 23**

22. To what extent do this child's health conditions or problems affect their ability to do things?

- a. Very little
- b. Somewhat

- c. A great deal
23. Does this child need or get special therapy, such as physical, occupational, or speech therapy?
- a. Yes
  - b. No
24. Does this child have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling?
- a. Yes
  - b. No
25. If **YES** to any of questions above in this Special Healthcare Needs section (Questions 19-24), is it because of ANY medical, behavioral, or other health condition that is expected to last 12 months or longer?
- a. Yes
  - b. No
  - c. All my responses to Questions 19-24 were NO

### *Your child's school/learning history*

***If your child is younger than 3 years old, go to question 46. If this child is between 3 and 5 years old, go to question 34.***

26. What grade is this child currently in? (If summer, what is the highest grade level this child has already completed)?
- a. Kindergarten
  - b. 1<sup>st</sup> grade
  - c. 2<sup>nd</sup> grade
  - d. 3<sup>rd</sup> grade
  - e. 4<sup>th</sup> grade
  - f. 5<sup>th</sup> grade
  - g. 6<sup>th</sup> grade
  - h. 7<sup>th</sup> grade
  - i. 8<sup>th</sup> grade
  - j. 9<sup>th</sup> grade
  - k. 10<sup>th</sup> grade
  - l. 11<sup>th</sup> grade
  - m. 12<sup>th</sup> grade
27. Since starting kindergarten, has this child repeated any grades?
- a. Yes
  - b. No



28. DURING THE PAST 12 MONTHS, about how many days did this child miss school because of their heart condition, illness, or injury?
- a. No missed school days
  - b. 1-3 days
  - c. 4-6 days
  - d. 7-10 days
  - e. 11 or more days
  - f. This child was not enrolled in school
29. Has this child EVER had any of the following special education or early intervention plans? (Select all that apply)
- a. Individualized Family Service Plan or IFSP (used for early intervention services in children younger than 3)
  - b. Individualized Education Program or IEP (used for special education services in children 3 or older)
  - c. 504 Plan (sometimes used for special education services instead of or in addition to an IEP)
  - d. Other, specify \_\_\_\_\_
  - e. No, this child has never had a plan for special education

**If your child is younger than 12 years old, go to question 31.**

30. How likely do you think it is that this child will...
- a. Get a regular high school diploma? A regular high school diploma includes a "GED" but does not include a certificate of completion or a special diploma for students in special education  
  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]
  - b. Attend school after high school? Including technical or trade school  
  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]
  - c. Attend a special training program after high school for persons with intellectual disabilities?  
  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has / Does not apply]
  - d. Complete a technical or trade school program?  
  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]
  - e. Graduate from a 2-year or community college?  
  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]
  - f. Graduate from a 4-year college?  
  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

- g. *Get a driver's license?*  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]
- h. *Eventually live away from home on their own without supervision?*  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]
- i. *Eventually live away on their own with supervision?*  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]
- j. *Eventually get a paid job? This includes any paid job -- child does not need to make enough to support self. This can include sheltered or supported employment.*  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]
- k. *Earn enough to support themselves without financial help from their family or government benefit programs?*  
[Definitely will / Probably will / Probably won't / Definitely won't / Don't know / Already has]

### *Your child's activities and social environment*

- 31. DURING THE PAST WEEK, on how many days did this child exercise, play a sport, or participate in physical activity for at least 60 minutes?
  - a. 0 days
  - b. 1-3 days
  - c. 4-6 days
  - d. Every day
  
- 32. DURING THE PAST 12 MONTHS, did this child participate in:
  - a. *A sports team or did he or she take sports lessons after school or on weekends?* [Yes/No]
  - b. *Any clubs or organizations after school or on weekends?* [Yes/No]
  - c. *Any other organized activities or lessons, such as music, dance, language, or other arts?*  
[Yes/No]
  - d. *Any type of community service or volunteer work at school, church, or in the community?*  
[Yes/No]
  - e. *Any work, including regular jobs as well as babysitting, cutting grass, or other occasional work?*  
[Yes/No]
  
- 33. DURING THE PAST 12 MONTHS, how often was this child bullied, picked on, or excluded by other children?
  - a. *Never*
  - b. *1-2 times (in the past 12 months)*

- c. *1-2 times per month*
- d. *1-2 times per week*
- e. *Almost every day*

34. Compared to other children their age, how much difficulty does this child have making or keeping friends?

- a. *No difficulty*
- b. *A little difficulty*
- c. *A lot of difficulty*

### *Your child's readiness to learn*

**Answer questions 35 – 45 only if your child is between 3 and 5 years old. Otherwise go to question 46.**

35. How often does this child share toys or games with other children?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

36. How often does this child show concern when they see others who are hurt or unhappy?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

37. How often does this child play well with other children?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

38. How often can this child recognize and name their own emotions?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

39. How often does this child have difficulty when asked to end one activity and start a new activity?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

40. How often does this child lose their temper?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

41. How often does this child have trouble calming down?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

42. How often does this child have difficulty waiting for their turn?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

43. How often does this child get easily distracted?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

44. How often can this child focus on a task you have given them for at least a few minutes? For example, simple chores?

- a. *Always*
- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

45. How often does this child keep working at a task even when it is hard for them?

- a. *Always*

- b. *Most of the time*
- c. *About half of the time*
- d. *Sometimes*
- e. *Never*

### *Your child's health care*

46. Where does this child usually go when they are sick or you need advice about their health?
- a. This child does not have a usual place for health care or advice when sick
  - b. Doctor's Office
  - c. Hospital Emergency Room
  - d. Hospital Outpatient Department
  - e. Urgent Care Center
  - f. Clinic or Health Center
  - g. Retail Store Clinic or "Minute Clinic"
  - h. School (Nurse's Office, Athletic Trainer's Office)
  - i. Some other place
47. DURING THE PAST 12 MONTHS, how many times did this child visit a doctor, nurse, or other health care professional to receive a PREVENTIVE check-up? A preventive check-up is when this child was not sick or injured, such as an annual or sports physical, or well-child visit.
- a. 0 visits
  - b. 1 visit
  - c. 2 or more visits
48. DURING THE PAST 12 MONTHS, how many times did this child visit a hospital emergency room?
- a. None
  - b. 1 time
  - c. 2 or more times
49. DURING THE PAST 12 MONTHS, was this child admitted to the hospital to stay for at least one night?
- a. Yes
  - b. No

### *Your child's unmet needs*

50. DURING THE PAST 12 MONTHS, did this child need any of the following health care but it was not received? (Select all that apply)
- a. Heart care
  - b. Other medical care
  - c. Dental care
  - d. Vision care
  - e. Hearing care
  - f. Mental health services

- g. Other, specify \_\_\_\_\_
- h. This child has received all the healthcare they needed in the past 12 months - **Go to question 52**

51. Did any of the following reasons contribute to this child not receiving needed health services?
- a. This child did not have health insurance that covered the services needed [Yes / No]
  - b. This child was not eligible for the services [Yes / No]
  - c. The services this child needed were not available in your area [Yes / No]
  - d. There were problems getting an appointment when this child needed one [Yes / No]
  - e. There were problems with getting transportation or child care [Yes / No]
  - f. I had too many other things going on [Yes / No]
  - g. The clinic or doctor's office wasn't open when this child needed care [Yes / No]
  - h. There were issues related to cost [Yes / No]
  - i. I chose to postpone or cancel appointments due to COVID-19 [Yes / No]
  - j. The clinic or doctor's office postponed or cancelled appointments due to COVID-19 [Yes / No]
  - k. Other, specify [Yes / No] \_\_\_\_\_

### *Your child's insurance*

52. Is this child CURRENTLY covered by ANY kind of health insurance or health coverage plan?
- a. Yes
  - b. No - **If this child is at least 12 years old, go to question 54. Otherwise go to question 60.**
53. Is this child CURRENTLY covered by any of the following types of health insurance or health coverage plans?
- a. Insurance through a current or former employer or union [Yes/No]
  - b. Insurance purchased directly from an insurance company, including the Health Insurance Marketplace from the Affordable Care Act (ACA) [Yes/No]
  - c. Medicaid (including MassHealth, MinnesotaCare, PeachCare, or Georgia Families), Medical Assistance, or any kind of government assistance plan for those with low incomes or a disability [Yes/No]
  - d. TRICARE or other military health care [Yes/No]
  - e. Indian Health Service [Yes/No]
  - f. Other, specify [Yes/No] \_\_\_\_\_

### *Transition to adult healthcare*

**Answer questions 54-59 only if this child is at least 12 years old. Otherwise go to question 60.**

54. Eligibility for health insurance often changes in young adulthood. Do you know how this child will be insured as he/she becomes an adult?
- a. Yes - **Go to question 56**
  - b. No

55. If no, has anyone discussed with you how to obtain or keep some type of health insurance coverage as this child becomes an adult?
- Yes
  - No
56. Has a doctor or other health care provider ever discussed with you this child's need to see a heart doctor throughout their life?
- Yes
  - No
57. Has this child's doctor or other health care provider actively worked with the child to:
- Make positive choices about his/her health? For example, by eating healthy, getting regular exercise, not using tobacco, alcohol or other drugs, or delaying sexual activity*
- [Yes / No / Don't know]
- Gain skills to manage his/her health and health care? For example, by understanding current health needs, knowing what to do in a medical emergency, or taking medications he/she may need*
- [Yes / No / Don't know]
- Understand the changes in health care that happen at age 18? For example, by understanding changes in privacy, consent, access to information, or decision-making*
- [Yes / No / Don't know]
58. How prepared do you feel this child is to make positive choices about his/her health, manage his/her own health and health care, and handle changes in health care that happen at age 18?
- Very prepared*
  - Somewhat prepared*
  - Not very prepared*
  - Not at all prepared*
59. Have this child's doctors or other health care providers worked with you and this child to create a plan of care to meet their health goals and needs?
- Yes
  - No
60. Please rate how concerned you are about this child's future health
- Very concerned*
  - Somewhat concerned*
  - Not very concerned*
  - Not at all concerned*

## Immunizations

61. DURING THE PAST 12 MONTHS, has this child had a flu vaccination? A flu vaccination is usually given in the fall and protects against influenza for the flu season.
- Yes
  - No

## COVID-19

62. Has this child ever had coronavirus or COVID-19 (based on a positive test for COVID-19 or a health professional telling you the child had COVID-19)?
- Yes
  - No
  - Did not receive results
63. Please select the statement that best describes this child regarding the COVID-19 vaccine:
- This child has received all recommended doses of vaccine for COVID-19 - **Go to question 65**
  - This child has received some but not all recommended doses of vaccine, and I intend for them to receive all recommended doses - **Go to question 65**
  - This child has received some but not all recommended doses of vaccine, and I do not intend for them to receive all recommended doses
  - This child has not received any vaccine for COVID-19
  - Other
64. What are your reasons for choosing not to get this child fully vaccinated for COVID-19? (Select all that apply)
- I'm concerned about the potential side effects of the vaccine
  - I feel the vaccines were created too quickly
  - I don't believe the vaccines are effective at preventing the spread of COVID-19
  - I'm not concerned about this child contracting COVID-19
  - I'm generally opposed to vaccinations
  - A friend or family member had a bad reaction to the vaccine
  - I don't think that a vaccine is necessary because COVID-19 is not a serious threat
  - This child's doctor advised me not to get this child vaccinated
  - Other, specify \_\_\_\_\_
  - I prefer not to say

## About you

65. How are you related to this child?
- Biological or adoptive parent*
  - Step-parent*
  - Grandparent*



- d. *Foster parent*
- e. *Other: Relative*
- f. *Other: Non-relative*

66. What is your age in years?

- a. \_\_\_\_\_ Numeric response

67. What is your marital status?

- a. Married
- b. Not married, but living with partner
- c. Never married
- d. Divorced
- e. Separated
- f. Widowed

68. What is the highest grade or level of school you have completed?

- a. *8th grade or less*
- b. *9th-12th grade; No diploma*
- c. *High School Graduate or GED Completed*
- d. *Completed a vocational, trade, or business school program*
- e. *Some College Credit, but no Degree*
- f. *Associate Degree (AA, AS)*
- g. *Bachelor's Degree (BA, BS, AB)*
- h. *Master's Degree (MA, MS, MSW, MBA)*
- i. *Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)*

69. Which of the following best describes your current employment status?

- a. *Employed full time*
- b. *Employed part-time*
- c. *Working WITHOUT pay*
- d. *Not employed but looking for work*
- e. *Not employed and not looking for work*

70. In general, how is your mental or emotional health?

- a. Excellent
- b. Very good
- c. Good
- d. Fair
- e. Poor

71. How well do you feel that you are handling the day-to-day demands of raising a child with a heart condition?

- a. Very well
- b. Somewhat well

- c. Not very well
- d. Not well at all

72. DURING THE PAST 12 MONTHS, was there someone that you could turn to for day-to-day emotional support with parenting or raising a child with a heart condition?

- a. Yes
- b. No – **Go to Question 74**

73. If yes, did you receive support from:

- a. Spouse or domestic partner? [Yes / No]
- b. Other family member or close friend? [Yes / No]
- c. Health care provider? [Yes / No]
- d. Place of worship or religious leader? [Yes / No]
- e. Support or advocacy group related to specific health condition? [Yes / No]
- f. Peer support group? [Yes / No]
- g. Counselor or other mental health professional? [Yes / No]
- h. Other person, specify [Yes / No] \_\_\_\_\_

74. DURING THE PAST 12 MONTHS, did your family have problems paying for any of this child's medical or health care bills?

- a. Yes
- b. No

75. DURING THE PAST 12 MONTHS, have you or other family members...

- a. *Left a job or taken a leave of absence because of this child's health or health conditions?* [Yes/No]
- b. *Cut down on the hours you work because of this child's health or health conditions?* [Yes/No]
- c. *Avoided changing jobs because of concerns about maintaining health insurance for this child?* [Yes/No]

76. IN AN AVERAGE WEEK, how many hours do you or other family members spend providing health care at home for this child? *Care might include changing bandages or giving medication and therapies when needed.*

- a. *This child does not need health care provided at home on a weekly basis*
- b. *Less than 1 hour per week*
- c. *1-4 hours per week*
- d. *5-10 hours per week*
- e. *11 or more hours per week*

77. At any time DURING THE PAST 12 MONTHS, even for one month, did anyone in your family receive:

- a. *Cash assistance from a government welfare program?* [Yes / No]
- b. *Food stamps or Supplemental Nutrition Assistance Program (SNAP) benefits?* [Yes / No]
- c. *Free or reduced-cost breakfast or lunches at school?* [Yes / No]
- d. *Benefits from the Women, Infants, and Children (WIC) program?* [Yes / No]

78. SINCE THIS CHILD WAS BORN, how often has it been very hard to cover the basics, like food or housing, on your family's income?
- a. *Never*
  - b. *Rarely*
  - c. *Somewhat often*
  - d. *Very often*

### *Household information*

79. Does this child have another parent or adult caregiver who lives in this household?
- a. *Yes*
  - b. *No - **Go to Question 83***

80. How is this other caregiver related to this child?
- a. *Biological or adoptive parent*
  - b. *Step-parent*
  - c. *Grandparent*
  - d. *Foster parent*
  - e. *Other: Relative*
  - f. *Other: Non-relative*

81. What is the highest grade or level of school this caregiver has completed?
- a. *8th grade or less*
  - b. *9th-12th grade; No diploma*
  - c. *High School Graduate or GED Completed*
  - d. *Completed a vocational, trade, or business school program*
  - e. *Some College Credit, but no Degree*
  - f. *Associate Degree (AA, AS)*
  - g. *Bachelor's Degree (BA, BS, AB)*
  - h. *Master's Degree (MA, MS, MSW, MBA)*
  - i. *Doctorate (PhD, EdD) or Professional Degree (MD, DDS, DVM, JD)*

82. Which of the following best describes this caregiver's current employment status?
- a. *Employed full time*
  - b. *Employed part-time*
  - c. *Working WITHOUT pay*
  - d. *Not employed but looking for work*
  - e. *Not employed and not looking for work*

83. How many children under the age of 18 are now living in the household, **not including this child**?
- a. *\_\_\_\_ Numeric response*

84. What is the primary *language* spoken in the household?

- a. *English*
- b. *Spanish*
- c. *Somali*
- d. *Other, specify \_\_\_\_\_*

### *Childhood experiences*

The next questions are about events that may have happened during this child's life. These things can happen in any family, but some people may feel uncomfortable with these questions. As a reminder, you may skip any questions you do not want to answer.

85. To the best of your knowledge, has this child EVER experienced any of the following?

- a. *Parent or guardian divorced or separated* [Yes / No]
- b. *Parent or guardian died* [Yes / No]
- c. *Parent or guardian served time in jail or prison* [Yes / No]
- d. *Saw or heard parents or adults slap, hit, kick, or punch one another in the home* [Yes / No]
- e. *Was a victim of violence or witnessed violence in their neighborhood* [Yes / No]
- f. *Lived with anyone who was mentally ill, suicidal, or severely depressed* [Yes / No]
- g. *Lived with anyone who had a problem with alcohol or drugs* [Yes / No]
- h. *Treated or judged unfairly because of their race or ethnic group* [Yes / No]
- i. *Treated or judged unfairly because of a health condition or disability* [Yes / No]

***If child is younger than 6, go to the next question (#86).***

- j. *Treated or judged unfairly because of their sexual orientation or gender identity* [Yes / No]

### *Future needs*

86. What expectations do you have for this child in the future?

- a. *[Free text response]*

87. What concerns do you have for this child in the future?

- a. *[Free text response]*

### *Contact information*

88. If you would like to receive *periodic* updates on the progress and results of this survey, please provide your email address.

*Public reporting burden for this collection of information is estimated to average 20 minutes, including completing and reviewing the collection of information. An agency may not conduct or sponsor and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road NE, MS D-74, Atlanta, GA 30333: ATTN: PRA (0920-1382).*